DOCUMENT RESUME

ED 375 118 SP 035 495

TITLE	What Black Women Should Know about Lupus: Ideas for Community Programs.
INSTITUTION	National Inst. of Arthritis and Musculoskeletal and Skin Diseases (NIH), Bethesda, MD.
REPORT NO	NIH-93-3445
PUB DATE	Sep 93
CONTRACT	NO1-AR-0-2201
NOTE	92p.; Prepared by the National Task Force on Lupus in High Risk Populations.
AVAILABLE FROM	National Institute of Arthritis and Musculoskeletal and Skin Diseases, Box AMS, 9000 Rockville Pike, Bethesda, MD 20892.
PUB TYPE	Guides - Non-Classroom Use (055)
EDRS PRICE	MF01/PC04 Plus Postage.
DESCRIPTORS	Adults; *Blacks; *Clinical Diagnosis; *Community Programs; *Females; Health Activities; *Health Education; Health Materials; Health Promotion; Program Design; Program Development; Resource Materials; Special Health Problems; Young Adults
IDENTIFIERS	*Lupus

ABSTRACT

Lupus is a serious health problem that mainly affects young women between the ages of 15 and 44. Although people of all races may get lupus, black women have three times higher rates of incidence, prevalence, and mortality than white women. With early detection and proper treatment, most people with lupus can lead a normal life. This kit is designed to help develop educational programs, plan activities to increase awareness about lupus in black women, and encourage early diagnosis of the disease. The kit is divided into four sections. The first section, "How to Develop a Lupus Awareness Program," provides a sample program plan and a list of activities to be used in schools or in the community. Section two, "How to Work with the Media," includes guidelines for working with public service announcements, and a sample newsletter article. The third section, "How To Use Camera-Ready Materials," provides instructions for production of a booklet titled "What Black Women Should Know about Lupus," a test of lupus knowledge, a bookmark, stationery, and logos. The final section, "How to Find Additional Resources," provides names and addresses of organizations that have additional information about lupus. A copy of "What Black Women Should Know About Lupus," a booklet to increase awareness about signs of the disease, an order form to request additional copies of this kit or the booklet, and an evaluation form complete the kit. (LL)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED 375 118

What Black Women Should Know About Lupus:
Ideas for Community Programs

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

☐ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

SB354/95

NATIONAL INSTITUTES OF HEALTH
National Institute of Arthritis and Musculoskeletal and Skin Diseases

2 BEST COPY AVAILABLE

The Task Force on Lupus in High Risk Populations uses the butterfly as its logo. This logo has special significance because one of the more common signs of lupus is a red rash or color change on the face, often in the shape of a butterfly, across the bridge of the nose and the cheeks.

SP

What Black Women Should Know About Lupus:
Ideas for Community Programs

Produced by the Task Force on Lupus in High Risk Populations
National Institute of Arthritis and Musculoskeletal and Skin Diseases

This material is not copyrighted. Readers are encouraged to duplicate and distribute it.
Additional copies are available from the NIAMS Task Force on Lupus in High Risk Populations, National Institute of Arthritis and Musculoskeletal and Skin Diseases, Box AMS, 9000 Rockville Pike, Bethesda, MD 20892.

CONTENTS

NOTE TO PROGRAM PLANNERS 1

ABOUT THIS KIT 3

HOW TO DEVELOP A LUPUS AWARENESS PROGRAM 7
- SAMPLE PROGRAM PLAN 9
- CREATIVE ACTIVITIES TO CONDUCT IN YOUR COMMUNITY 11

HOW TO WORK WITH THE MEDIA 19
- SAMPLE PUBLIC SERVICE ANNOUNCEMENTS 23
- SAMPLE LETTER TO PUBLIC SERVICE DIRECTOR 26
- FILL-IN-THE-BLANKS PRESS RELEASE 27
- SAMPLE LETTER TO THE EDITOR 28
- SAMPLE FEATURE STORY PITCH LETTER 29
- HEALTH WATCH: BLACK WOMEN AND LUPUS 30

HOW TO USE THESE CAMERA-READY MATERIALS 33
- *WHAT BLACK WOMEN SHOULD KNOW ABOUT LUPUS* 35
- POSTER 47
- FACTS ABOUT LUPUS AND BLACK WOMEN 49
- CHECKLIST ON SIGNS OF LUPUS 51
- TEST OF LUPUS KNOWLEDGE 52
- BILL STUFFER/BOOKMARK 54
- STATIONERY 55
- LOGOS 57

HOW TO FIND ADDITIONAL RESOURCES 61
- RESOURCES FOR COMMUNITY PROGRAM PLANNING 62
- EDUCATIONAL MATERIALS ABOUT LUPUS 63

APPENDIX
- MEMBERS OF THE TASK FORCE ON LUPUS IN HIGH RISK POPULATIONS 75

NOTE TO PROGRAM PLANNERS

If you are concerned about the health of black women, you can make a difference. You can help raise awareness in your community about lupus in young black women and encourage them to see a doctor if they have symptoms of the disease. This kit presents a variety of ideas you can use to develop educational programs on lupus for black women. It is based on successful programs on lupus and other health topics that have been carried out throughout the country.

Lupus is a serious health problem that mainly affects young women. The disease often starts between the ages of 15 and 44. People of all races may get lupus. However, black women have three times higher rates of incidence (number of new cases), prevalence (total number of cases), and mortality than white women. They tend to develop the disease at a younger age than white women and to develop more serious complications. **As many as 1 in 250 black women will get the disease**.

Lupus is often hard to diagnose because it is similar to many other diseases. Many in the black community have never heard of lupus, and it often goes undiagnosed until serious complications arise. Lupus may damage the joints, skin, kidneys, lung, heart, or brain.

Lupus can be serious, but with early detection and proper treatment, most people with lupus can lead a normal life. Researchers sponsored by the National Institutes of Health (NIH) are making significant progress in lupus. An NIH research team has determined the most effective drug treatment for the kidney disease of lupus--and found that this treatment can prevent the most serious kidney damage. Other NIH-supported research is helping women with lupus have successful pregnancies. And the lead NIH Institute for lupus research, the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) has just launched a series of research initiatives aimed at determining the causes of lupus, more precisely how it damages the organs, and why it is more common in women and minorities, particularly African-American women. The NIAMS also will be funding the first two Federally funded research centers ever devoted to lupus.

Until research provides the answers to lupus, the NIAMS also is sponsoring the Task Force on Lupus in High Risk Populations. The purpose of the Task Force is to develop education strategies directed to patients, the public, and health professionals that may help improve the outcome of lupus in populations at high risk of developing the disease.

The Task Force has determined that the highest priority audience for lupus education efforts is young black women. We believe that an effective way to reach these women is through efforts carried out in community settings.

We present this kit of ideas to program planners and others involved in community programs and encourage you to help get the word out to young black women about the symptoms of lupus and the need to see a doctor if they arise. If you would like assistance or materials, please contact the Task Force on Lupus in High Risk Populations, National Institute of Arthritis and Musculoskeletal and Skin Diseases, Box AMS, 9000 Rockville Pike, Bethesda, Maryland 20892. We welcome your comments and would like to hear about how these ideas and materials are being used and how they might be improved.

Task Force on Lupus in High Risk Populations

ABOUT THIS KIT

What Black Women Should Know About Lupus: Ideas for Community Programs is designed to help you plan activities and programs to increase awareness about lupus in black women. This kit is part of an ongoing effort to encourage early diagnosis of lupus. We need your help.

Programs on lupus generated by previous efforts of the Task Force on Lupus in High Risk Populations have been carried out in a variety of settings ranging from soup kitchens to churches to Federal, state, and local clinics. These efforts are described in "Creative Community Programs." (See page 12.)

Please use the materials in this kit to increase awareness about lupus in your community. Activities you plan can inform women about lupus and encourage them to: (1) recognize the signs of lupus, (2) see their doctor if they are experiencing signs of lupus, and (3) realize that early diagnosis and appropriate medical care will improve the quality of their lives.

This kit is divided into four sections:

- How To Develop a Lupus Awareness Program--provides guidelines for developing a successful lupus awareness program, a sample program plan, and a list of activities that you can organize for members of your community.

- How To Work With the Media--provides guidelines for working with the media, public service announcements and a cover letter to send to public service directors, a fill-in-the-blanks press release, a sample letter to the editor, a sample feature story pitch letter, and a sample newsletter article.

- How To Use These Camera-Ready Materials--provides instructions for production of the following camera-ready materials: a booklet entitled *What Black Women Should Know About Lupus*, a poster, a factsheet about lupus in black women, a checklist on signs of lupus, a test of lupus knowledge, a bill stuffer, a bookmark, stationery that can be used to send information or letters to media representatives and community leaders, and logos that you can use on your own materials.

- How To Find Additional Resources--provides the names and addresses of organizations that have additional information about lupus and can help you plan activities for your community, references to community program planning materials, and references to educational materials about lupus.

In the back pocket of the kit is a popular educational booklet *What Black Women Should Know About Lupus*. The pocket also contains a poster that can be used to increase awareness about the signs of lupus, an order form to request additional copies of this kit or the booklet, and a response form to return to the Task Force so that we can evaluate the effectiveness of this kit.

HOW TO DEVELOP A LUPUS AWARENESS PROGRAM

9

BEST COPY AVAILABLE

HOW TO DEVELOP A LUPUS AWARENESS PROGRAM

To develop a program plan like the one shown on page 9, start by answering the following questions.

Who is your target audience?

The target audience for this campaign is **black women between the ages of 15 and 44**. You may want to choose activities that will reach various age ranges within the target audience. For example, a poster contest for students will reach 15- to 18-year-olds while brown-bag lunches held at various worksites will reach women ages 20 to 44.

Objectives

- Increase awareness and knowledge of lupus in black women and the general public.
- Increase the number of women who recognize signs of lupus.
- Increase the number of women who seek medical care when experiencing the signs of lupus.

What are your objectives?

You may wish to adopt one or more of the objectives listed above. If you decide to create your own objectives, make sure you set objectives that allow you to measure the success of your program. For example, if you choose to "increase the number of women who recognize the signs of lupus," you can measure the success of your program by counting the number of women who are familiar with the signs before and after each activity. If more women recognize the signs of lupus after participating in one of your program activities, the activity can be considered a success.

What messages will you use to inform your audience about lupus?

Messages should be easy to understand and support your objectives. If your objective is to "increase the number of women who recognize the signs of lupus," your message should include the signs of lupus. Other messages from a sample program plan are listed on page 9.

What materials will help you achieve your objectives?

The materials in this kit are designed to help meet the Task Force objectives. Use them or change them so they will help you reach **your** target audience.

Designing materials can be one of the activities used to increase awareness about lupus. Target audience members can learn about lupus while creating posters, exhibits, and other materials.

What activities will most effectively reach the target audience in your community?

Choose activities that will appeal to the people you are trying to reach. Check out the ideas listed in "Creative Activities To Conduct in Your Community" (page 11).

Ask other local groups to participate in the activity. For example, if you would like to plan a brown-bag lunch, major employers in your community can participate by encouraging their employees to attend, providing convenient space for the event, and donating drinks or dessert.

How can local groups help you?

Local groups can participate in activities, and/or they may be willing to donate volunteer time, supplies, money, or other services. A local printer may be willing to print lupus awareness materials free of charge. Local clothing merchants may lend clothes for a fashion show. Schools may help organize a poster contest for students. A utility company or other business could include brief informational material in a monthly billing.

How can the media help you?

Choose media activities that will foster lupus awareness and/or promote the events you are planning. Refer to "How To Work With the Media" (page 19).

How can you tell if your program is a success?

Evaluation requires planning. The type of evaluation you do will depend on the activities and objectives that you choose. To properly assess the effectiveness of your program, you may need to conduct a survey before and after activities. For example, if one of your objectives is to "increase the number of women who seek medical care when experiencing signs of lupus," you may wish to survey a local health clinic before and after you implement your program. You could find out how many women are aware of the signs of lupus and the importance of seeking medical care when experiencing these signs. If more women are aware of lupus after your program, you have succeeded.

Proper evaluation involves many steps not explained in this kit. Refer to *Making Health Communications Work: A Planner's Guide*, published by the National Cancer Institute, for a complete description of the evaluation process. (See "Resources for Community Program Planning," page 62, for information about how to obtain a free copy of this manual.)

NOTE: If you would like additional information about community program planning, please refer to "Resources for Community Program Planning" (page 62).

SAMPLE PROGRAM PLAN

Target Audience:

- Black women between the ages of 15 and 44.

Objectives:

- Increase awareness and knowledge of lupus in black women and the general public.
- Increase the number of women who recognize signs of lupus.
- Increase the number of women who seek medical care when experiencing signs of lupus.

Messages:

- Common signs of lupus are: red rash or color change on the face, painful or swollen joints, unexplained fever, chest pain with breathing, unusual loss of hair, pale or purple fingers or toes from cold or stress, sensitivity to the sun, and low blood count.
- The signs of lupus are more important when they occur together.
- If you have signs of lupus, see your doctor.
- Early diagnosis is important.
- Early diagnosis and appropriate treatment will relieve the signs of lupus and improve your life.
- The Lupus Foundation of America (LFA) and The American Lupus Society (TALS) have additional information about lupus and provide physician referrals.
- Lupus is a serious disease.
- Lupus is treatable.

Materials:

Poster
Booklet
Resource list
Table tent cards
Bill stuffers
Radio PSA's

Other Resources:

Donated printing from local printers
Speakers for potluck suppers

Groups To Involve:

Businesses:	Largest employers of black women in your area. Local utility company. Local shopping malls and department stores.
Organizations:	Selected churches and chapters of the LFA and TALS.
Health Care Providers:	Local hospitals with community outreach programs. Community health centers.
Community Services:	Public libraries. Local junior and senior high schools.

Community Activities:

- Organize potluck suppers at selected churches.
- Organize brown-bag lunches at selected worksites.
- Distribute lupus awareness materials in libraries, hospitals, and community health centers.
- Ask a local utility company to use bill stuffers.
- Hold a lupus poster contest (for students) offering donated prizes. Exhibit entries in a mall and later at local schools.

Media Activities:

- Ask a spokesperson to appear on two call-in shows on black-oriented radio programs with formats targeted to black listeners.
- Provide local stations/on-air personalities with the live-announcer copy in this kit.

Evaluation:

- Track the number of materials distributed.
- Track call-in show response.
- Ask health care providers, in advance of your program, to keep track of how many patients are asking about the signs of lupus.
- Ask potluck and brown-bag participants to see how many signs of lupus they can list after hearing the presentation.
- Ask local chapters of the LFA and TALS if they are receiving additional requests for information.
- Survey schools before and after the poster contest to see how many students are familiar with the signs of lupus.

CREATIVE ACTIVITIES TO CONDUCT IN YOUR COMMUNITY

How can you get the word out about lupus?

Your organization can do many kinds of activities alone or in cooperation with other groups to increase awareness about lupus in black women. The activities listed below will work in a variety of community locations. Later in the list we have offered suggestions for specific settings. You can change or combine the activities to meet your local needs.

- Ask your local chapters of the Lupus Foundation of America, Inc. (LFA) or The American Lupus Society (TALS) to help you plan programs or seminars for your organization. (See "How To Find Additional Resources," page 61.)

- Invite a health professional to come talk to your group about lupus. Tell him or her you want to know about symptoms, treatment, and research advances. A local hospital or the local chapters of the LFA or TALS may be able to recommend a speaker.

- Talk to your local hospital to see if they have a community health education program that could include lupus as a topic.

- Hold a breakfast for employers, religious leaders, or media representatives, and ask them to co-sponsor activities with you.

- Form an African-American outreach committee to distribute materials to local African-American organizations such as fraternities, sororities, or civic clubs.

- Publish lupus information in organization newsletters or magazines, using the reproducible art and articles from this kit. Include information about local resources.

- Hold or participate in health fairs at community centers, churches, and schools. Include an exhibit about lupus.

- Display or distribute the booklet *What Black Women Should Know About Lupus* at your public library. Ask the librarians to distribute copies, and suggest that they hang the poster and place materials on display.

- Contact recreation centers about putting on programs or distributing materials.

Creative Community Programs

Examples of creative approaches successfully used by other communities include:

- In Florida, a retired Episcopalian minister held **seminars and meetings**. He encouraged predominantly black congregations in the state to declare a 'Lupus Awareness Sunday,' asking clergy to talk about lupus and to reproduce the booklet *What Black Women Should Know About Lupus* in the Sunday church bulletin. Many congregations chose a Sunday during October, National Lupus Awareness Month.

- The New York chapter of the Lupus Foundation of America, Inc. (LFA) held **health fairs** at community centers, churches with predominantly black congregations, and high schools, including a writing competition at one school where a teacher has lupus. In addition, the chapter placed posters about lupus on subways and buses.

- The United Methodist Church (UMC) is developing a **model program** offering a variety of activities. It will be tested in 15 churches with predominantly black congregations in the Baltimore/ Washington area. If successful, the UMC will distribute the program to its churches throughout the United States.

- A soup kitchen in Detroit used slides to create a **video** that has been shown to more than 30,000 women. In addition, it distributed copies of the booklet *What Black Women Should Know About Lupus.*

- The Bronx, New York, chapter of the LFA, under the direction of an ordained minister, held meetings and seminars at churches with predominantly black congregations and distributed material at day care centers in the Bronx. In addition, this chapter plans to distribute several thousand copies of the booklet *What Black Women Should Know About Lupus* at the national meeting of the Baptist Church to be held in New York City's Madison Square Garden.

- The Atlanta chapter of the LFA conducted seminars about lupus at Historically Black Colleges and Universities, such as Spellman College and Morehouse University in Atlanta, and distributed copies of the booklet.

BEST COPY AVAILABLE

- Ask a sponsor to imprint refrigerator magnets with the signs of lupus that you can give away or sell at events, or give as gifts for volunteers.

- Create bookmarks that list the signs of lupus.

- Conduct a lupus awareness bake sale. You can place posters listing the signs of lupus behind the sale tables, distribute materials about lupus in minority populations, and borrow a videotape about lupus from your local library to play during the sale.

- Organize a 1-day boat cruise for lupus awareness. The signs of lupus could be printed on cruise tickets. Materials about lupus could be distributed upon boarding. Volunteers from a local chapter of the LFA or TALS could arrange a short presentation during lunch or dinner.

- Hold a lupus awareness "potluck supper." Invite a lupus patient and/or expert to talk about lupus in black women.

Hospitals or Clinics

- Place posters and materials about lupus and black women in lobbies and waiting areas.

- Ask lupus experts to present at hospital grand rounds devoted to the topic of lupus in black women.

- Include an exhibit and materials about lupus at your next health fair.

- Arrange for a Continuing Medical Education (CME) course about lupus to be given for physicians in your area.

Schools or Youth Programs

- Ask high school clubs or art classes to design and construct banners or portable exhibits for use at community events. Display the exhibit at schools, community centers, churches, health centers, and offices.

- Hold a lupus poster contest (for students) offering donated prizes. Exhibit entries in a mall, community center, library, local airport, or other public place.

- Hold a "rap" contest about lupus in minorities. Local radio or TV stations can help promote the contest and play the winning entries.

- Invite local churches to sponsor a lupus awareness dance, bringing youth from the area together at one church. It could be a "danceathon" to raise money as well as awareness. Combine the dance with the rap contest by having rappers judged by applause.

- Ask local Parent-Teacher Associations (PTA's) or Parent-Teacher-Student Associations (PTSA's) to distribute lupus awareness materials at meetings and events.

- Organize a lupus awareness car wash. You can place posters listing the signs of lupus nearby and have a table where people can pick up other materials about lupus in minority populations while they are waiting for their car.

SPECIAL EVENTS CALENDAR

Link local events with national events. Take advantage of important local dates and community events, including parades, county fairs, health fairs, picnics, family reunions, block parties, high school reunions, and sports competitions.

Black History Month	February
National Women's History Month	March
Mother's Day	May
National Council of Negro Women's Black Family Weekend	Summer/Fall
National Lupus Awareness Month	October

Worksites

- Place posters about lupus and black women on office or corridor bulletin boards.

- Place information about lupus in black women on electronic bulletin boards.

- Reprint and distribute the factsheets and artwork to coworkers.

- Hold a brown-bag lunch about lupus. Invite a lupus patient and her doctor to discuss their experiences. Borrow a videotape about lupus from your local library to show during the brown-bag lunch.

- Ask employers/businesses to print and display table tent cards using the reproducible art from this kit or to use payroll or bill stuffers (especially for utility company, bank, and credit card statements).

- Ask local businesses if they have printing capabilities and can reprint materials from this kit. (Offer to acknowledge their donation on the materials.)

- Ask unions to distribute lupus awareness materials to members.

Churches

- Encourage clergy and lay leaders to promote lupus awareness and its potential effects on black families. Ask churches to include articles in their weekly bulletin or to distribute brochures after services or social events.

- Consider the activities in the first part of this list. Many of these ideas are ideal for the church setting. Also consider the activities described in "Creative Community Programs." (See page 12.)

Retail Outlets

- Hold a health fair with other organizations at a shopping mall or office building. Ask the local chapter of the LFA or TALS for information about how to get things started.

- Ask merchants to display posters and table tent cards, use bag stuffers for customers, or include a lupus awareness message on store receipts. Encourage them to distribute factsheets and booklets.

Print Media

- Send newspapers and newsletters copy for public service print ads, such as the *Signs of Lupus* bill stuffer/bookmark. Ask them to run an article or editorial.

- Write a news release, op-ed piece, or letter to the editor to announce your new program. (See "How To Work With the Media," page 19.)

- Notify the calendar editors of local newspapers about the location, date, and time of your special event.

- Submit some ideas for local stories about lupus in black women to newspaper editors and to freelance health writers, and offer your group as an information source. You may want to have a lupus patient available for interviews to discuss the importance of early detection.

- Distribute the *Health Watch* article (see page 30) to smaller daily and weekly newspapers, "shoppers," and community organization publications. They almost always can use more material.

- Provide local stations/on-air personalities with PSA's. (See samples on pages 23-25.)

- Ask a cable TV station or regular program host to help you produce a program about lupus. After the broadcast, use the videotape in community programs.

- Meet with public service directors of television stations, including cable television, to discuss the importance of reaching their viewers with early detection information. Ask for help in producing local public service messages using the early detection theme.

- Arrange for a lupus expert or a spokesperson for your program to appear on a television or radio talk show.

- Ask producers of radio call-in shows and television public affairs programming to feature lupus. Offer to provide background information on lupus, sample questions and answers, and a lupus expert or patient to interview.

- Arrange to have your activities listed in a "community calendar" spot aired by television stations or cable television outlets.

- Encourage producers of television "magazine" shows to produce a segment about the importance of early detection of lupus.

- Work with public affairs directors to develop on-air editorials about lupus and black women.

Activities for Mother's Day

- Ask an alumni association, sorority, or auxiliary of a local medical society to sponsor a mother-daughter brunch around the topic of "What Mothers and Daughters Need To Know About Lupus."

- Stage a fashion show for mothers and daughters. Ask local clothing stores to lend outfits to be modeled by mothers or daughters. The store gets free advertising at the fashion show and in all promotional materials, such as flyers, etc. Mothers and daughters enjoy modeling the clothes. You can invite a speaker to talk about lupus, play a videotape, or just distribute materials that describe lupus signs. You also may ask the store to display a lupus poster.

- Organize a walkathon for lupus. Mothers and daughters or entire families can walk together.

HOW TO WORK WITH THE MEDIA

20

HOW TO WORK WITH THE MEDIA

The local media is always interested in stories with a local angle. They provide numerous opportunities to inform young black women about lupus.

This section tells you how to use the materials in this kit to get maximum media coverage of your local efforts. By working closely with radio and television stations, newspapers, newsletters, and other publications, you can really "get the word out" about lupus.

Develop a List

First, develop--or update--your list of local media contacts. If you have never done this before, start by consulting a media directory that lists reporters in your area. *Bacon's Publicity Checker* is a standard media directory and is available at most public libraries (referenced in "Resources for Community Program Planning," page 62). Call selected contacts to confirm that the information is up to date. Also, regularly scan newspapers and monitor radio and TV shows to learn the names of reporters who cover health topics.

When you call or visit the people on your media list, ask about deadlines, special interests, and informational needs. Add this information to your list. Try to include representatives from:

- Radio stations.
- Television stations, including local network affiliates, independent stations, and cable outlets.
- Regional and national news services such as the nearest bureau of the Associated Press.
- Daily and weekly newspapers.
- Community advertisers' publications ("shoppers").
- Publications of civic, service, religious, fraternal, business, and health professional organizations.

Important contacts will include: assignment editors, health and news reporters assigned to cover health and local issues, and television public affairs directors. In addition, business-page editors can help you publicize worksite activities, and "calendar" editors can announce your events. Talk show hosts and/or their producers also are good media contacts when arranging interviews.

Use the Media Materials in This Kit

This section contains the following:

- 20-, 30-, and 60-second public service announcements (PSA's) for use by radio announcers.
- A cover letter to public service directors to accompany the PSA's.
- A "fill-in-the-blanks" press release.
- A sample letter to the editor.
- A sample feature story pitch letter.
- A sample newsletter article--*Health Watch: Black Women and Lupus.*

Adapt the press release and PSA's to meet your needs. Add other kit materials, such as the factsheet, the "health watch" article, and the booklet, as well as information about your own organization, and you have an informative mailing for the local media. Please refer to "Creative Activities To Conduct in Your Community" (page 11) for additional ideas about how to work with the media.

Public Service Announcements (PSA'S)

Create new PSA's about the special programs or local events that your organization is sponsoring. See the PSA's and cover letter provided on pages 23-25 for ideas. Select spots appropriate to each radio station. Rock stations are interested in announcements aimed at teenagers. Radio stations programming jazz, classical music, or talk shows are interested in announcements aimed at adults. If using the PSA's to promote a local event, mail or deliver them 2 to 4 weeks in advance.

Press Releases

Press releases are standard publicity tools, and reporters and editors receive many on a weekly basis. To draw attention to your release, add local information and retype it double spaced (or one-and-one-half spaces), using only one side of your letterhead. If possible, keep it to no more than two pages. Send the press release to health reporters of newspapers, local newsletters, and radio and TV stations at least 1 week before your event.

The headline and the lead sentence should "grab" the reader. Focus on what is "new," an upcoming event (with date), or a connection with a "hot" topic or other recent news story to create immediate interest.

Keys to Success

- Keep letters to the editor and editorials short. Op-ed pieces can be longer.
- Make sure your arguments are logical and your tone is persuasive.
- Provide background information, copies of recent news releases, or other stories about your program to convince editors that you are knowledgeable about the subject, a credible source, and that your editorial or op-ed is important to the community.
- Ask for and follow style guidelines, and deliver your piece on or before the paper's deadline.

Editorials, Op-Eds, and Letters to the Editor

The editorial section is one of the most widely read parts of the paper. This is a good place to express a viewpoint or announce new facilities or services. Editorial pages often include letters to the editor and op-eds.

Op-eds are articles, usually 500 to 800 words long, that carry an author's byline. They appear on the page opposite the editorial page and present an expert point of view on a specific topic. For example, an op-ed might argue for greater efforts in your community to get young black women with lupus diagnosed sooner.

To place an editorial or op-ed piece, address your article to the editorial page editor, or, in a smaller newspaper, the editor-in-chief. At television stations, which sometimes deliver editorials on important local issues, call the editorial writer or general manager.

Feature Stories

Call the health reporter or a feature writer to schedule an appointment. It is important that you already have the "hook" for the story or news item. For example, the fact that lupus is three times more common in black women than in white women is a hook. If it sparks interest, describe the signs of lupus and explain the importance of early diagnosis. Take along a package of background information about lupus, including the press release, booklet, factsheet, and "health watch" article. If a personal meeting is not possible, send the information and follow up with a telephone call. Ask directly whether the reporter is going to do a story on your subject. If yes, try to get a specific timeframe so you can look for the story.

Tips for Television

- ✓ Avoid clothes with checks, stripes, and patterns. Select medium tone colors in clothing (not too dark or too bright).
- ✓ Avoid solid white blouses and shirts. Medium to light shades give the best effect.
- ✓ Avoid flashy accessories and jewelry that will catch the light. Don't wear glasses that turn dark in sunlight; they will darken under the strong TV lights.
- ✓ Resist the temptation to bend into the microphone; sit or stand up straight. Don't fold your arms.
- ✓ Keep your eyes on the interviewer. Do not look at the camera or studio monitor.
- ✓ Use natural gestures, but avoid rapid hand movements that are difficult for the camera to follow.
- ✓ Never assume you are off camera just because someone else is talking; you may still be in range.

Identify Spokespersons Who will Work With You

Select one or more media spokespersons. These individuals should be very knowledgeable about lupus. One possibility is a local rheumatologist who treats patients with the disease and keeps up to date on new developments in the field. Your spokespersons also should be available and willing to respond to calls from the media. If an interview will be aired on TV or radio, the spokesperson should be articulate and able to respond to questions in terms understood by a lay audience. The local chapter of the Lupus Foundation of America, Inc. (LFA) or The American Lupus Society (TALS) may be able to help you identify a spokesperson.

Get the Interview

Once you have identified a spokesperson, contact a newspaper reporter or a talk show host. Give the interviewer background information about the spokesperson, including a biography that highlights his or her recent experience and connection with lupus. Also provide background information about lupus that answers a few suggested questions.

Help your spokesperson prepare for the interview. Let him/her know when and where the interview will be held. Review how the person would handle controversial or delicate questions, if they were asked.

Radio interviews can be conducted by phone. If the interview will be televised, give the spokesperson information about how to make the most of a TV appearance. (See "Tips for Television," page 21.)

Always Say "Thank You"

Send a thank-you letter to reporters, interviewers, and interviewees who help you, regardless of how brief the mention.

Some General Tips on Media Contacts

- Emphasize what is unique and compelling about the campaign when talking to reporters and others about your activities. The information in the enclosed factsheet will help you think ahead about questions that may be asked.
- Give reporters enough lead time to cover your story--about 1 week for a press release and 2 weeks for a feature story. Follow up with a phone call to see if they received your mailing.
- Make your followup calls brief and concise. Never call around deadline times. If you aren't sure when deadlines are, simply ask if the reporter is on deadline and when you should call back.
- If you send your materials to more than one person in an organization, make sure each recipient knows.
- One or 2 days before a special event, contact the local bureau of a national news service to have the event publicized in the "daybook." The daybook is a calendar listing checked daily by print and electronic media outlets. Look for *Bacon's Publicity Checker* in your library for the nearest bureau of the Associated Press, United Press International, or Reuters, Ltd. These are the three major news services used by daily newspapers.

SAMPLE PUBLIC SERVICE ANNOUNCEMENT

LUPUS?

Live Announcer Radio
:20 Version

ANNCR: *(Uses serious, yet dramatic inflections in voice)*

Lupus is a serious disease that makes a lot of young women sick--but it doesn't have to.

ANNCR: *(Returns to normal voice)*

Lupus is hard to recognize because the symptoms differ from one person to the next.

The *good news* is that lupus can be treated.

Learn more about lupus . . . . See your doctor and contact your local chapter of the Lupus Foundation of America today.

SAMPLE PUBLIC SERVICE ANNOUNCEMENT

LUPUS?

Live Announcer Radio
:30 Version

ANNCR: *(Uses serious, yet dramatic inflections in voice)*

Lupus is a serious disease that makes a lot of young women sick--but it doesn't have to.

ANNCR: *(Returns to normal voice)*

In lupus, something goes wrong with the body's immune system so that it damages the body's own tissues. The causes of lupus are unknown. We do know that lupus is not catching . . . it's not cancer . . . it's not AIDS . . . and there **are treatments**.

Lupus is hard to recognize because the symptoms differ from one person to the next.

The *good news* is that lupus can be treated.

Learn more about lupus . . . . See your doctor and contact your local chapter of the Lupus Foundation of America today.

SAMPLE PUBLIC SERVICE ANNOUNCEMENT

LUPUS?
Live Announcer Radio
:60 Version

ANNCR: *(Uses serious, yet dramatic inflections in voice)*

There's a disease out there that's making a lot of young women sick--but it doesn't have to . . . it's LUPUS.

ANNCR: *(Returns to normal voice)*

In lupus, something goes wrong with the body's immune system so that the body damages its own tissues. What causes lupus is still unknown. What we do know is that lupus is not catching . . . it's not cancer . . . it's not AIDS . . . and there **are treatments**.

Lupus is hard to recognize because the signs of lupus differ from one person to the next. Learn the signs of lupus:

- Red rash or color change on face, often in the shape of a butterfly, across the bridge of the nose and the cheeks.
- Painful or swollen joints.
- Unexplained fever.
- Chest pain with breathing.
- Unusual hair loss.
- Pale or purple fingers or toes from cold or stress.
- Sensitivity to the sun.
- Low blood count.

The *good news* is that lupus can be treated by your doctor. If you have some of these signs and they occur together, help is available. See your doctor and start feeling better today.

This message is brought to you by this station and the Task Force on Lupus in High Risk Populations of the National Institutes of Health.

SAMPLE LETTER TO PUBLIC SERVICE DIRECTOR

Dear Public Service Director:

The enclosed PSA's are about lupus--a serious, yet little-known disease that mainly affects young women. People of all races may develop lupus. However, lupus is nine times more common in women than men and three times more common in black women than white women. The causes of lupus are unknown. What is known is that lupus can affect many parts of the body, including the skin, kidneys, lungs, heart, or the brain. In lupus, the body's immune system sometimes becomes overactive and attacks healthy tissues.

While there is no cure for lupus, the *good news* is that great advances have been made in its treatment. Because of early diagnosis and treatment, women with lupus are living longer and more productive lives. It is for this reason that (Name of Organization) is planning activities to inform women about lupus.

We need your help to raise the level of awareness of lupus and its treatments. Please use these 20-, 30-, and 60-second live announcer scripts as often as possible so that your listeners will know the signs of lupus and seek a doctor for treatment.

If you have questions or recommendations, please contact me by writing (Organization Address and Phone).

Thank you for your assistance.

Sincerely,

Director of Organization

FILL-IN-THE-BLANKS PRESS RELEASE

FOR IMMEDIATE RELEASE
Date

CONTACT: Name
Telephone Number

(Organization) has joined a nationwide campaign to raise awareness of lupus and its signs among black women.

The campaign, "What Black Women Should Know About Lupus," is intended to raise awareness of lupus and its signs among black women and encourage them to see their doctor if they have signs of the disease, said (Name) of (Organization).

"Many in the black community have never heard of lupus, and it often goes undiagnosed until serious complications arise," said (Local Physician). "If left untreated, the disease may damage the joints, skin, kidneys, lungs, heart, or brain." (Local Physician) added that with the correct medicine, and by taking care of themselves, most lupus patients can hold a job, have children, and lead a full life.

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), a part of the National Institutes of Health, is urging groups to organize events and programs that will inform black women about lupus. In many cities, organizations are expected to sponsor special events and distribute material at worksites, churches, and other community settings. Locally, (Name) said activities will include (List Activities).

The NIAMS believes that women who think they have lupus should be examined by a doctor and tested for the disease. Lupus is a serious health problem that mainly affects young women. Although people of all races may get lupus, it has a three times higher incidence, prevalence, and mortality in black women than in white women. As many as 1 in 250 black women will develop lupus.

(SAMPLE LETTER TO THE EDITOR)

WHY BLACK WOMEN NEED TO KNOW ABOUT LUPUS

Dear Editor:

Lupus is a serious health problem that mainly affects young women. The disease often starts between the ages of 15 and 44. Although people of all races may get lupus, it is three times more common in black women than in white women. As many as 1 in every 250 black women will get this disease. Currently, black women with systemic lupus have a lower life expectancy than white women with the same disease.

Lupus can affect many systems of the body, including the heart, lungs, kidneys, and central nervous system. The body's immune system sometimes becomes overactive and attacks healthy tissues. Early diagnosis is the best defense against lupus.

Lupus is difficult to diagnose and is often mistaken for other diseases. Unfortunately, many women who have lupus are not diagnosed until serious complications occur. Diagnosis is based on an accurate patient history and laboratory tests. Therefore, it is important for women to know and provide their own complete medical history, especially if they see a different physician each time they require medical attention.

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), a part of the National Institutes of Health, urges groups to organize events and programs that will inform black women everywhere about lupus. The (Name of Local Organization) is planning (Event) on (Date(s)) to raise awareness of lupus and its signs in the black community. The goal is to encourage black women to see their doctor if they have signs of the disease. We hope that, armed with knowledge about lupus, black women will be able to fight the disease and increase their life expectancy.

If you would like additional information about lupus, call or write to: (Please fill in the name of your organization, or you may list the organizations from the resource list in this kit, page 61.)

Sincerely,

SAMPLE FEATURE STORY PITCH LETTER

Dear _____:

Lupus is a serious health problem that mainly affects young women and especially affects black women. The disease often starts between the ages of 15 and 44. Although people of all races may get lupus, it is three times more common in black women than in white women. As many as 1 in 250 black women will get the disease.

Lupus is difficult to diagnose and often is mistaken for other diseases. Frequently, people who have lupus are not diagnosed until serious complications occur. One example is the story of _____ who lives in the _____ area.

(Describe story of local woman who was diagnosed after serious complications--or had difficulty obtaining an accurate diagnosis.)

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), a part of the National Institutes of Health, urges groups to organize events and programs that will inform black women about lupus. We enclose additional information about lupus and the importance of early diagnosis. Please consider joining this national awareness effort with a local angle or feature story about lupus. (Person's Name) at the (Name of Your Organization) will be glad to assist you by arranging interviews with one or more women who have lupus, with local physicians, and other key experts.

Thank you for taking the time to consider this important health issue. We look forward to talking with you soon.

Sincerely,

(NOTE: Local chapters of the Lupus Foundation of America, Inc. or The American Lupus Society may be able to help you locate physicians, experts, and patients who are willing to be interviewed.)

HEALTH WATCH: BLACK WOMEN AND LUPUS

Did you know that lupus is a disease that occurs more frequently in young black women than in any other group? As many as 1 in 250 black women will get the disease. Lupus can be serious, but with early detection and proper treatment, most people with lupus can lead a normal life.

Considering these facts, it is important that black Americans, particularly young black women, know about lupus, its signs, and its treatment.

Lupus is a disease that can affect many parts of the body. In lupus, something goes wrong with the body's immune system. The immune system sometimes becomes overactive and attacks healthy tissues.

There are three types of lupus. The most serious of these is systemic lupus erythematosus, which may harm the skin, joints, kidneys, brain, lungs, and heart. Discoid or cutaneous lupus mainly affects the skin. Drug-induced lupus is caused by a small number of prescription medications and usually goes away when the medication is stopped.

How can you tell if you or someone you know has lupus? The signs of lupus differ from one person to another. Some people have many signs of the disease. Others have just a few. The common signs of lupus are:

- Red rash or color change on the face, often in the shape of a butterfly, across the bridge of the nose and the cheeks.
- Painful or swollen joints.
- Unexplained fever.
- Chest pain with breathing.
- Unusual loss of hair.
- Pale or purple fingers or toes from cold or stress.
- Sensitivity to the sun.
- Low blood count.

These signs are more important when they occur together.

Only a doctor can diagnose lupus. If you think you or someone you know has lupus, see a doctor right away. A doctor or nurse will talk to you and take a history of your health problems. The doctor will perform an examination and test for the disease.

The cause of lupus is unknown. However, scientists have learned a great deal about lupus and are studying new ways to treat and, hopefully, prevent the disease.

FOR MORE INFORMATION, call the Lupus Foundation of America, Inc. at (800) 558-0121 or The American Lupus Society at (800) 331-1802, or write to the Task Force on Lupus in High Risk Populations, National Institute of Arthritis and Musculoskeletal and Skin Diseases, Box AMS, 9000 Rockville Pike, Bethesda, Maryland 20892.

HOW TO USE THESE CAMERA-READY MATERIALS

HOW TO USE THESE CAMERA-READY MATERIALS

Materials in this section have been designed to be reproduced or adapted to your needs. The following camera-ready materials are included:

- Booklet.
- Poster.
- Factsheet.
- Checklist on signs of lupus.
- Test of lupus knowledge.
- Bill stuffer/bookmark.
- Stationery.
- Logos.

The kit has no copyright, so you may copy these materials without permission. Consider using your organization's logo, name, address, and telephone number on these easy-to-copy materials. Use them in a variety of ways.

- Handouts at health fairs, events, presentations, and meetings.
- Inserts in mailings or paycheck envelopes.
- Copy for newsletters.
- Bulletin board notices.
- Giveaways at hospitals and clinics.

Note: For additional ideas, see "Creative Activities To Conduct in Your Community," pages 11 to 16.

If you do not have the equipment to duplicate materials, you may need to contact a printer. Printers' prices for similar work may vary depending on arrangements made. Selection of a printer depends on a number of considerations--meeting your deadline, budget, and quality needs. Before contacting the printer for estimates on reproduction costs, determine the size, as well as the number of copies needed, of each item; select color and type of paper; and select a due date for delivery of your copies. Be sure to determine the level of reproduction quality and discuss any special requirements.

Instructions for Production

The booklet "What Black Women Should Know About Lupus"

This product should be copied onto paper that is 8 1/2- by 11-inches. The artwork pieces on pages 35 to 46 are designed to back each other up and should be copied double-sided. Then, copies should be folded in half and saddle stitched (stapled in the center) to create a booklet that is 4 1/4 inches wide and 5 1/2 inches high. If you would like a replica of the booklet found in the back pocket of this kit, please give the printer the following specifications:

Size:	Enlarge to 9 1/4 x 12 inches
Cover stock:	80# litho-coated paper
Color:	PMS 299 C and black
Cover text:	reverse white
Cover art:	black
Text stock:	60# opaque white paper

The poster "What Black Women Should Know About Lupus"

This product can be copied onto 8 1/2- by 11-inch brightly colored paper. The poster found in the back pocket of this kit is printed on 80# litho-coated paper. The color used is PMS 299 C. The text is reverse white and the artwork is printed in black.

The factsheet "Facts About Lupus and Black Women"

This product is double-sided and should be copied onto 8 1/2- by 11-inch paper. The factsheet may get more attention if printed on colored paper.

"Checklist on Signs of Lupus"

The checklist can be distributed at activities or reprinted in newsletter or newspaper articles. It is designed to be a 4- by 7-inch card. Copy the checklist onto heavy stock paper. Ask the printer to cut the copies for you. Crop lines are provided for this purpose.

Test of knowledge "Do You Know Enough About Lupus?"

Camera-ready artwork for *Do You Know Enough About Lupus?* is provided in two formats. The first design is for use as a table tent card. It should be copied onto 8 1/2- by 11-inch heavy stock paper and folded in the middle. Tell the printer that the paper must be thick enough to stand up on its own. Also, ask the printer to fold the tent cards for you. The second design can be distributed as a handout or reprinted in newsletters.

Bill stuffer/bookmark "Signs of Lupus"

This item can be used as a bill stuffer or as a bookmark. The finished product will be 3 inches wide and 7 inches long. The printer can fit three copies on each piece of paper. This will save paper and money. Ask the printer to cut the copies for you.

If you plan to use bill stuffers, copy the artwork onto plain or colored paper. If you would like bookmarks, copy the artwork onto a colorful, heavy stock paper (perhaps glossy coated). In addition, you can send a copy of *Signs of Lupus* to newspapers and newsletters for use as a public service print ad.

U. S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
National Institutes of Health
National Institute of Arthritis and Musculoskeletal and Skin Diseases

36

NIH Publication No. 93-3219
September 1993

What Black Women Should Know About Lupus

NATIONAL INSTITUTES OF HEALTH
National Institute of Arthritis and Musculoskeletal and Skin Diseases

Prepared by the
NIAMS Task Force on Lupus in High Risk Populations
National Institute of Arthritis and Musculoskeletal and Skin Diseases
Box AMS
9000 Rockville Pike
Bethesda, Maryland 20892

The NIAMS, a part of the National Institutes of Health,
leads and coordinates the Federal biomedical research effort in lupus.

This booklet is not copyrighted. Readers are encouraged to duplicate and distribute as many copies as needed. Additional copies are available from the NIAMS Task Force on Lupus in High Risk Populations, National Institute of Arthritis and Musculoskeletal and Skin Diseases, Box AMS, 9000 Rockville Pike, Bethesda, Maryland 20892. Comments and suggestions about this booklet or other possible booklets are welcome.

Checklist on Signs of Lupus

Use this page to make notes to take to your doctor

_____ Red rash or color change on face, often in the shape of a butterfly across the bridge of the nose and the cheeks

_____ Painful or swollen joints

_____ Unexplained fever

_____ Chest pain with breathing

_____ Unusual loss of hair

_____ Pale or purple fingers or toes from cold or stress

_____ Sensitivity to sun

_____ Low blood count

These signs are more important if they occur together.

Do You or Someone You Know Have Signs of Lupus?

Lupus is a serious health problem that affects mainly young women. The disease often starts between the ages of 15 and 44.

People of all races may get lupus. However, lupus is three times more common in black women than in white women.

As many as one in 250 black women will get the disease.

What is Lupus?

Lupus is a disease that can affect many parts of the body. It can affect the joints, the skin, the kidneys, the lungs, the heart, or the brain. Only a few of these parts of the body are affected in most people.

Something goes wrong with the body's immune system in lupus. We can think of the immune system as an army within the body with hundreds of defenders (known as antibodies).

They defend the body from attack by germs and viruses. In lupus, however, the immune system becomes overactive and goes out of control. The antibodies attack healthy tissues in the body. This attack induces inflammation, causing redness, pain, and swelling in the affected parts of the body. This tendency for the immune system to become overactive may run in families.

What Does a Person with Lupus Look Like?

Many people with lupus look healthy.

What Are the Signs of Lupus?

The signs of lupus differ from one person to another. Some people have just a few signs of the disease; others have more. Lupus may be hard to diagnose. It is often mistaken for other diseases. For this reason, lupus has often been called the "great imitator."

Common signs of lupus are:

- Red rash or color change on the face, often in the shape of a butterfly across the bridge of the nose and the cheeks
- Painful or swollen joints
- Unexplained fever
- Chest pain with breathing
- Unusual loss of hair
- Pale or purple fingers or toes from cold or stress
- Sensitivity to the sun
- Low blood count

These signs are more important when they occur together.

have learned a great deal about lupus and are studying new ways to treat and, hopefully, prevent the disease. The future holds great promise for improving the health of all Americans who have lupus.

Awareness

Please share this booklet with your family and friends. Someone you know or care about may have lupus.

For further information on lupus, see your doctor or health clinic and contact your local chapter of the following organizations:

Lupus Foundation of America, Inc.
4 Research Place
Suite 800
Rockville, Maryland 20850-3226
(301) 670-9292
(800) 558-0121

The American Lupus Society
3914 Del Amo Blvd.
Suite 922
Torrance, California 90503
(310) 542-8891
(800) 331-1802

Both of these groups can provide more detailed information on lupus through free pamphlets and newsletters. They also have pamphlets in Spanish. The two groups also can refer people to doctors and clinics who see a lot of lupus patients.

How is Lupus Treated?

The doctor may treat each lupus patient in a different way because the signs of lupus often differ from one person to another. The doctor may give aspirin or similar medicine to treat the painful, swollen joints and the fever. Creams may be prescribed for the rash, and stronger medicines prescribed for more serious problems.

Is There a Cure for Lupus?

At this point, lupus cannot be cured. However, in many cases, signs of the disease can be relieved. The good news is that with the correct medicine and by taking care of themselves, most lupus patients can hold a job, have children, and lead a full life.

Outlook

The outlook for lupus patients has greatly improved. Research doctors supported by the National Institutes of Health are studying many aspects of lupus, such as what goes wrong with the immune system, why the disease runs in families, how lupus causes damage in the body, and why it can lead to repeated miscarriages. Others are researching why lupus is so much more common in women, especially black women. Researchers

Other signs of lupus can include mouth sores, unexplained "fits" or convulsions, hallucinations or depression, repeated miscarriages, and unexplained kidney problems.

What Causes Lupus?

We don't know what causes the immune system to become overactive. In some people, lupus becomes active after exposure to sunlight, infections, or certain medications.

Can You Catch Lupus From Someone Else?

No, lupus is not catching. You can't give it to someone else. Also, it is not a form of cancer. It is not AIDS.

Does Lupus Run in Families?

Most relatives of lupus patients do not develop the disease, but in some families more than one member gets lupus. If a relative of a lupus patient develops signs of lupus, she or he should see a doctor.

How Serious is Lupus?

Signs of lupus tend to come and go. There are times when the disease quiets down, or goes into remission. At other times, lupus flares up, or becomes active. Years ago, many people with lupus died. Now, with good medical care, most people with the disease can lead active, productive, and fulfilling lives.

Are There Different Kinds of Lupus?

There are three major types of lupus: (1) lupus that affects certain parts of the body (systemic lupus erythematosus), (2) lupus mainly of the skin (discoid or cutaneous lupus), and (3) lupus caused by medicine (drug-induced lupus).

Systemic lupus erythematosus, sometimes called SLE, is the most serious form of the disease. This type of lupus is the focus of this booklet. Systemic means that it may affect many parts of the body, such as the joints, skin, kidneys, lungs, heart, or the brain. This type of lupus can be mild or serious. If it is not treated, systemic lupus can cause damage to the organs inside your body.

Discoid and cutaneous lupus mainly affect the skin. The person may have a red rash or a color change of the skin on the face, scalp, or other parts of the body.

Drug-induced lupus is caused by a small number of prescription medications. The person with drug-induced lupus may have the same symptoms as the person with systemic lupus, but it is usually less serious. Usually when the medicine is stopped, the disease goes away. The most common drugs that can cause lupus are (1) procainamide used for heart problems, (2) hydralazine used for high blood pressure, and (3) dilantin used for seizures. Drug-induced lupus is usually found in older men and women of all races.

Does Sunlight Cause Lupus?

In some people, no matter what shade of skin, an attack of lupus may be brought on by being in the sun, even for a short period of time.

Do Men Get Lupus?

Yes, men get all forms of lupus. However, 9 out of 10 people who have lupus are women.

Why is Lupus More Common in Black Women Than White Women?

We do not know why the disease is more common in black women. However, research doctors supported by the National Institutes of Health are studying this problem. Researchers are studying why minorities are more inclined to get lupus, what causes it to start, and why is it mild in some and severe in others. Other researchers are studying why the signs of lupus differ between black women and white women.

What Should You Do if You Think You Have Lupus?

You should see a doctor or a nurse and be examined and tested for lupus. They will talk to you and take a history of your health problems. Many people have lupus for a long time before it is detected. It is important that you tell the doctor or nurse about your symptoms. (The checklist in the back of the booklet may be helpful.)

What Black Women Should Know About Lupus

Common Signs of Systemic Lupus

- Red rash or color change on the face, often in the shape of a butterfly across the bridge of the nose and the cheeks
- Painful or swollen joints
- Unexplained fever
- Chest pain with breathing
- Unusual loss of hair
- Pale or purple fingers or toes from cold or stress
- Sensitivity to the sun
- Low blood count

These signs are more important when they occur together.

For further information on lupus, see your doctor or health clinic and contact your local chapter of the following organizations:

Lupus Foundation of America, Inc.
4 Research Place
Suite 800
Rockville, Maryland 20850-3226
(310) 670-9292
(800) 558-0121

The American Lupus Society
3914 Del Amo Blvd.
Suite 922
Torrance, California 90503
(310) 542-8891
(800) 331-1802

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service National Institutes of Health
Task Force on Lupus in High Risk Populations

FACTS ABOUT LUPUS AND BLACK WOMEN

Who Gets Lupus?

- Lupus is a serious health problem that mainly affects young women. The disease often starts between the ages of 15 and 44. People of all races may get lupus. However, lupus is three times more common in black women than in white women. As many as 1 in 250 black women will get the disease.

- You cannot catch lupus from someone else. You cannot give lupus to someone else. Lupus is not a form of cancer. It is not AIDS.

What Is Lupus?

- In lupus, the body produces abnormal antibodies that react against the patient's own tissues. Lupus may affect the joints, the skin, the kidneys, the lungs, the heart, or the brain.

There Are Three Types of Lupus:

- Systemic lupus erythematosus, the most serious form of lupus, which may harm the skin, joints, kidneys, brain, lungs, and heart.

- Lupus that mainly affects the skin (discoid or cutaneous lupus).

- Lupus caused by a small number of prescription medications (drug-induced lupus), which goes away when the medication is stopped.

Common Signs of Systemic Lupus:

- Red rash or color change on the face, often in the shape of a butterfly, across the bridge of the nose and the cheeks.

- Painful or swollen joints.

- Unexplained fever.

- Chest pain with breathing.

- Unusual loss of hair.

- Pale or purple fingers or toes from cold or stress.

- Sensitivity to the sun.

- Low blood count.

These signs are more important when they occur together.

Other signs of lupus can include mouth sores, unexplained fits or convulsions, hallucinations, depression, repeated miscarriages, and unexplained kidney problems.

Signs of lupus tend to come and go. There are times when the disease quiets down or goes into remission. At other times lupus flares up or becomes active.

Diagnosis and Treatment:

- Only a doctor can diagnose lupus. If you think you or someone you know has lupus, see a doctor right away. A doctor or nurse will talk to you and take a history of your health problems. The doctor will perform an examination and test for the disease.

- The doctor may prescribe a variety of medications for the lupus patient.

- If you have lupus, you may need extra rest. Try to avoid stressful situations, and stay out of the sun. Some people should avoid sunlight because it may worsen the disease.

- We do not know what causes lupus, but scientists are looking for a cure. Scientists also are improving ways to detect and treat the disease.

For More Information:

- Call the **Lupus Foundation of America, Inc.** at (800) 558-0121 or **The American Lupus Society** at (800) 331-1802, or write to the **Task Force on Lupus in High Risk Populations**, National Institute of Arthritis and Musculoskeletal and Skin Diseases, Box AMS, 9000 Rockville Pike, Bethesda, Maryland 20892.

Prepared by the
NIAMS Task Force on Lupus in High Risk Populations
National Institute of Arthritis and
Musculoskeletal and Skin Diseases

NIAMS, a part of the National Institutes of Health, leads and coordinates the Federal biomedical research efforts in lupus.

CHECKLIST ON SIGNS OF LUPUS

Use this page to make notes to take to your doctor.

- ❒ Red rash or color change on face, often in the shape of a butterfly, across the bridge of the nose and the cheeks.
- ❒ Painful or swollen joints.
- ❒ Unexplained fever.
- ❒ Chest pain with breathing.
- ❒ Unusual loss of hair.
- ❒ Pale or purple fingers or toes from cold or stress.
- ❒ Sensitivity to the sun.
- ❒ Low blood count.

These signs are more important when they occur together.

NOTES:

DO YOU KNOW ENOUGH ABOUT LUPUS?

As many as 1 in 250 black women will develop lupus. Do you know enough about lupus to protect yourself and your friends from the complications of this disease? Answer the following questions and read the answers provided on the back to learn more.

		True	False	Not Sure
1.	Black women are three times more likely to develop lupus than white women.	❒	❒	❒
2.	Lupus is easy to diagnose.	❒	❒	❒
3.	Lupus usually affects young women.	❒	❒	❒
4.	Lupus can be treated.	❒	❒	❒
5.	All people who have lupus experience a rash in the shape of a butterfly across the bridge of their nose and cheeks.	❒	❒	❒
6.	Lupus is always fatal.	❒	❒	❒
7.	A person with some of the following signs should see a doctor. Common signs of lupus include: painful or swollen joints, unexplained fever, chest pain with breathing, unusual loss of hair, pale or purple fingers or toes from cold or stress, red rash or color change on the face, sensitivity to the sun, and low blood count.	❒	❒	❒

fold here

ANSWERS TO *DO YOU KNOW ENOUGH ABOUT LUPUS?*

1. True.
2. False. Lupus can be difficult to diagnose and is often mistaken for other illnesses. The doctor can test for lupus, but also needs an accurate and complete patient history. You are the only person who can describe your symptoms.
3. True. Lupus usually develops in young women between the ages of 15 and 44.
4. True. It is important to visit a doctor if you have signs of lupus. Early diagnosis and treatment may prevent serious complications.
5. False. Some patients experience a red rash or color change on the face, but some never do.
6. False. With early medical care, most people who have lupus can lead active, productive, and fulfilling lives.
7. True. These signs are more important when they occur together. If you are experiencing signs of lupus, please visit your doctor or health clinic.

If you would like additional information about lupus, please contact your local chapter of the following organizations:

Lupus Foundation of America, Inc.
4 Research Place
Suite 800
Rockville, Maryland 20850-3226
(800) 558-0121

The American Lupus Society
3914 Del Amo Boulevard
Suite 922
Torrance, California 90503
(800) 331-1802

DO YOU KNOW ENOUGH ABOUT LUPUS?

As many as 1 in 250 black women will develop lupus. Do you know enough about lupus to protect yourself and your friends from the complications of this disease? Answer the following questions and read the answers provided to learn more.

		True	False	Not Sure
1.	Black women are three times more likely to develop lupus than white women.	❒	❒	❒
2.	Lupus is easy to diagnose.	❒	❒	❒
3.	Lupus usually affects young women.	❒	❒	❒
4.	Lupus can be treated.	❒	❒	❒
5.	All people who have lupus experience a rash in the shape of a butterfly across the bridge of their nose and cheeks.	❒	❒	❒
6.	Lupus is always fatal.	❒	❒	❒
7.	A person with some of the following signs should see a doctor. Common signs of lupus include: painful or swollen joints, unexplained fever, chest pain with breathing, unusual loss of hair, pale or purple fingers or toes from cold or stress, red rash or color change on the face, sensitivity to the sun, and low blood count.	❒	❒	❒

If you are experiencing signs of lupus, please visit your doctor or health clinic. If you would like additional information about lupus, please contact your local chapter of the following organizations:

Lupus Foundation of America, Inc.
4 Research Place
Suite 800
Rockville, Maryland 20850-3226
(800) 558-0121

The American Lupus Society
3914 Del Amo Boulevard
Suite 922
Torrance, California 90503
(800) 331-1802

ANSWERS

1. True.
2. False. Lupus can be difficult to diagnose and is often mistaken for other illnesses. The doctor can test for lupus, but also needs an accurate and complete patient history. You are the only person who can describe your symptoms.
3. True. Lupus usually develops in young women between the ages of 15 and 44.
4. True. It is important to visit a doctor if you have signs of lupus. Early diagnosis and treatment may prevent serious complications.
5. False. Some patients experience a red rash or color change on the face, but some never do.
6. False. With early medical care, most people who have lupus can lead active, productive, and fulfilling lives.
7. True. These signs are more important when they occur together.

Signs of Lupus

1. Red rash or color change on face, often in the shape of a butterfly, across the bridge of the nose and the cheeks.

2. Painful or swollen joints.

3. Unexplained fever.

4. Chest pain with breathing.

5. Unusual loss of hair.

6. Pale or purple fingers or toes from cold or stress.

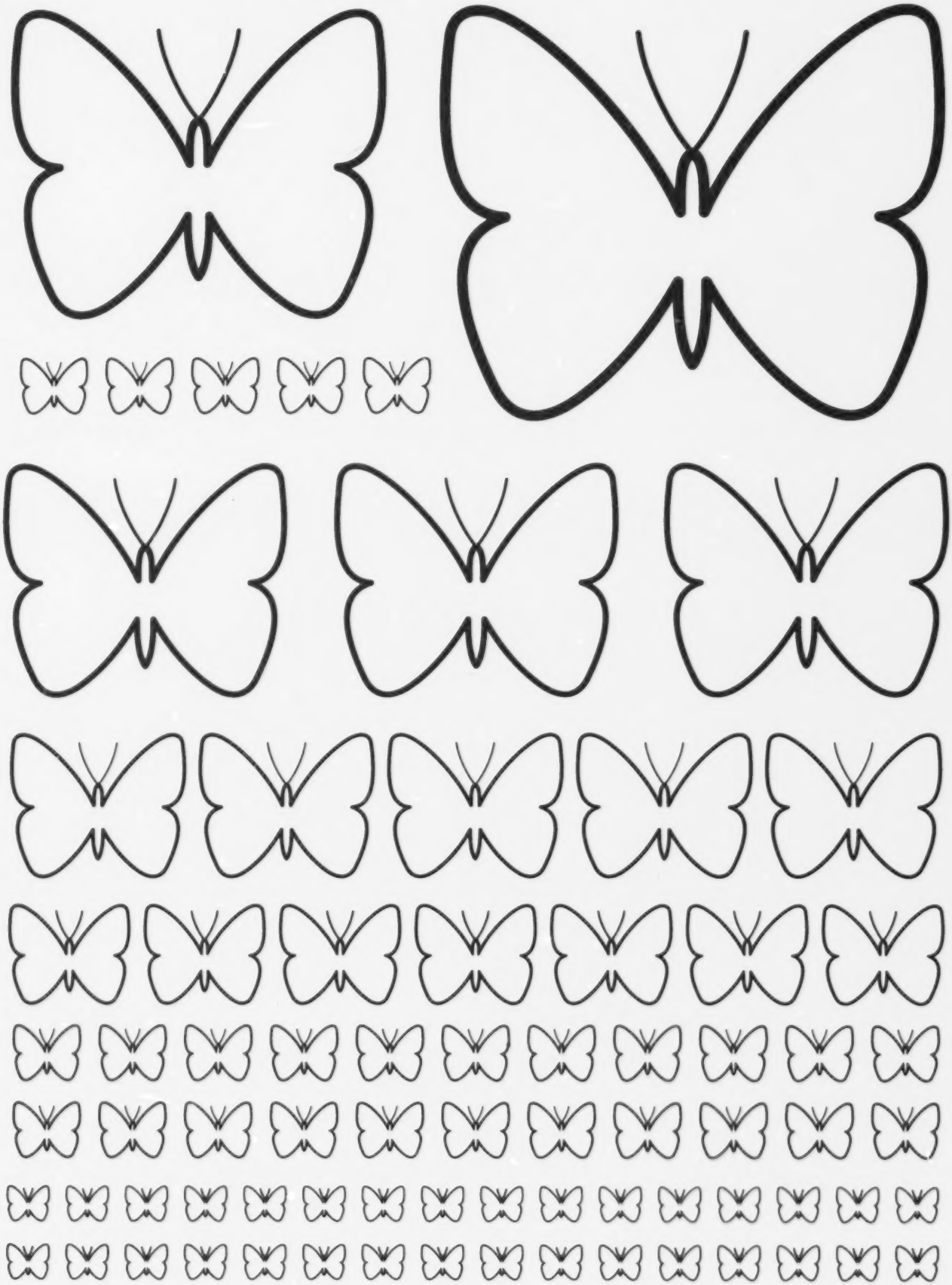
7. Sensitivity to the sun.

8. Low blood count.

For further information, visit your doctor or health clinic and contact your local chapter of the following organizations:

The Lupus Foundation of America, Inc.
4 Research Place
Suite 180
Rockville, Maryland 20850-3226
(800) 558-0121

The American Lupus Society
3914 Del Amo Boulevard
Suite 922
Torrance, California 90503
(800) 331-1802



HOW TO FIND ADDITIONAL RESOURCES

HOW TO FIND ADDITIONAL RESOURCES

Lupus Foundation of America, Inc.
(LFA)
4 Research Place
Suite 180
Rockville, Maryland 20850-3226
(800) 558-0121

The American Lupus Society (TALS)
3914 Del Amo Boulevard
Suite 922
Torrance, California 90503
(800) 331-1802

These organizations, which can provide a list of their chapters around the country, publish booklets and newsletters and have programs about the causes, symptoms, and treatment of lupus. They also can make medical referrals.

National Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse
Box AMS
9000 Rockville Pike
Bethesda, Maryland 20892
(301) 496-8188

The National Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse (NAMSIC) is a national resource center for information about professional, patient, and public education materials; community demonstration programs; and Federal programs related to rheumatic, musculoskeletal, and skin diseases. The Clearinghouse maintains a bibliographic database of educational materials from which it produced Lupus Patient Education Materials: An Annotated Bibliography. This list of resources contains 162 citations to educational materials for patients and their families about the symptoms, diagnosis, and treatment of lupus. The bibliography is available for $4 from the Clearinghouse.

RESOURCES FOR COMMUNITY PROGRAM PLANNING

Bacon's Media Directories: Publicity Checker, Radio/TV Directory, Media Alerts, Chicago, IL: Bacon's Information, Inc., 1993. Order from Bacon's Information, Inc., 332 S. Michigan Avenue, Chicago, IL 60604. (800) 621-0561.

Burrelle's Black/Hispanic Media Directory, Livingston, NJ: Burrelle's Media Directories, 1992. Order from Burrelle's Media Directories, 75 E. Northfield Road, Livingston, NJ 07039. (800) 631-1160.

Chisnall, Peter M., *Marketing Research*, New York: McGraw Hill, 1986. Order from McGraw Hill, Inc., 1221 Avenue of the Americas, New York, NY 10020. (800) 338-3987.

Green, Lawrence W. and Lewis, Frances M., *Measurement and Evaluation in Health Education and Health Promotion*, Palo Alto, CA: Mayfield Publishing Co., 1986. Order from Mayfield Publishing Company, 1240 Villa Street, Mountain View, CA 94041. (800) 433-1279.

Kline, Mark; Chess, Caron; and Sandman, Peter, *Evaluating Risk Communication Programs: A Catalogue of "Quick and Easy" Feedback Methods*, Trenton, NJ: New Jersey Dept. of Environmental Protection, 1990. Order from Maps and Publications Sales Office, New Jersey Bureau of Revenue, CN417, Trenton, NJ 08625. (609) 777-1039.

Locating Resources for Healthy People 2000 Health Promotion Projects, Washington, DC: Office of Disease Prevention and Health Promotion, 1991. Order from ODPHP National Health Information Clearinghouse, P.O. Box 1133, Washington, DC 20013-1133. (800) 336-4797.

Making Health Communications Work: A Planner's Guide, Bethesda, MD: National Cancer Institute, 1992. Order from Office of Cancer Communication, 9000 Rockville Pike, Bethesda, MD 20892. (800) 422-6237.

Promoting Issues and Ideas: A Guide to PR for Nonprofit Organizations, New York: The Foundation Center, 1987. Order from The Foundation Center, 79 5th Avenue, New York, NY 10003. (800) 424-9836.

EDUCATIONAL MATERIALS ABOUT LUPUS

Fact Sheets, Booklets, and Books

Arthritis Information: Systemic Lupus Erythematosus (Lupus).
Atlanta, GA: Arthritis Foundation. June 1990. [20 p.].
Available from Arthritis Foundation. P.O. Box 19000, Atlanta, GA 30326. (800) 283-7800. PRICE: Single copy free.

This brochure discusses the disease process of lupus and defines the two types, discoid and systemic. In a question-and-answer format, the brochure addresses the causes, types of people affected, diagnosis, and treatment.

Coping with Lupus: A Guide to Living with Lupus for You and Your Family.
Phillips, R.H.
New York, NY: Avery Publishing Group. 1991. 276 p.
Available from Lupus Foundation of America, Inc. 4 Research Place, Suite 180, Rockville, MD 20850-3226. (301) 670-9292 or (800) 558-0121. PRICE: $8.00.

This handbook, written in a relaxed, informal style by a practicing psychologist, describes strategies and techniques aimed to improve the quality of life of people with lupus and their families.

Fact Sheets.
Akron, OH: Lupus Foundation of America, Akron Area Chapter.
Available from the Lupus Foundation of America, Akron Area Chapter. 942 N. Main Street, #23, Akron, OH 44310. (216) 253-1717. PRICE: Free.

A series of nine fact sheets about lupus written at a low reading level.

Facts About Lupus.
Rockville, MD: Lupus Foundation of America, Inc. 1992.
Available from the Lupus Foundation of America, Inc. 4 Research Place, Suite 180, Rockville, MD 20850-3226. (301) 670-9292 or (800) 558-0121. PRICE: $3.95 per series.

A series of brochures on a wide range of lupus-related topics including lifestyle, pregnancy, skin, kidneys, central nervous system, etc.

Learning About Lupus: A User Friendly Guide.

Moore, M.E.; McGrory, C.H.; Rosenthal, R.S., eds.

Wayne, PA: MainLine DeskTop Publishing Company. 1991. 85 p.

Available from Lupus Foundation of Delaware Valley, Inc. 44 West Lancaster Avenue, Ardmore, PA 19003. (215) 649-9202. PRICE: $5.00 per copy plus $1.50 postage.

This book, written by medical advisory board members of the Lupus Foundation of Delaware Valley in Pennsylvania, is targeted for newly diagnosed patients and provides an overview of the multi-organ involvement that may occur in lupus.

Living With It: Why You Don't Have to Be Healthy to Be Happy.

Szasz, S.

Buffalo, NY: Prometheus Books. 1991. 243 p.

Available from Prometheus Books. 700 East Amherst Street, Buffalo, NY 14215. (716) 837-2475 or (800) 421-0351. PRICE: $22.95. ISBN: 0879756594.

This book is the personal account of a woman who was diagnosed with systemic lupus erythematosus (SLE) at the age of 13. She recounts the story of her illness, how it affected her adolescence and adulthood, and her experiences as a survivor.

Lupus: A Guide for Patients.

Hughes, G.R.V.

Torrance, CA: The American Lupus Society. 25 p.

Available from The American Lupus Society. 3914 Del Amo Boulevard, Suite 922, Torrance, CA 90503. (310) 542-8891 or (800) 331-1802. PRICE: $3.00.

This pamphlet discusses all major aspects of lupus, including its history, clinical features, various forms, testing, treatment, medication, research, and prognosis.

Lupus and Pregnancy.

Rosinsky, L.

Heliogram. April 1990. [6 p.].

Available from Lupus Network. 230 Ranch Drive, Bridgeport, CT 06606. (203) 372-5795. PRICE: $1.50.

This fact sheet provides a comprehensive review of lupus and pregnancy presented in a question and answer format. Questions addressed include: will lupus interfere with the ability to get pregnant; will lupus symptoms flare during pregnancy; are any special tests needed; and will the baby inherit lupus.

Lupus and Women of Color.

San Jose, CA: Lupus Foundation of America, Bay Area Chapter. 6 p.
Available from the Lupus Foundation of America, Bay Area Chapter. 2635 North First Street, Suite 206, San Jose, CA 95134. (408) 954-8600. PRICE: Single copies free.

This brochure briefly explains the symptoms and characteristics of SLE. A checklist is provided for people to determine if they may have one or more of the symptoms. Information is included on the activities of the Bay Area Lupus Foundation. This brochure is also available in Spanish and Vietnamese.

Lupus and You.

Reinertsen, J.L.

Minneapolis, MN: Park Nicollet Medical Foundation. 1986. 2nd Edition. 32 pages.
Available from the Arthritis Center, Park Nicollet Medical Foundation. 5000 West 39th Street, Minneapolis, MN 55416. (612) 924-2755. PRICE: $2.00; 10% discount for 25-100 copies; 20% discount for 100+ copies.

This booklet is intended to help people with lupus understand what it is, what effects it might have on their lives, and what they can do to help themselves and their doctors in the management of the disease. A glossary of lupus-related terms is included.

Lupus Eritematoso. [Lupus Erythematosus].

Torrance, CA: The American Lupus Society. 1993. 18 p.
Available from The American Lupus Society. 3914 Del Amo Boulevard, Suite 922, Torrance, CA 90503. (310) 542-8891 or (800) 331-1802. PRICE: $2.00.

This booklet, written in Spanish, is for lupus patients. It provides a brief history of lupus, as well as the causes, diagnosis, symptoms, and treatment of the disease. A glossary is included.

Lupus Erythematosus: A Handbook for Physicians, Patients & Their Families.

Carr, R.

Rockville, MD: Lupus Foundation of America, Inc. 1986. 60 p.
Available from the Lupus Foundation of America, Inc. 4 Research Place, Suite 180, Rockville, MD 20850-3226. (301) 670-9292 or (800) 558-0121. PRICE: $3.95

Lupus Erythematosus: A Patient's Guide.

DuBois, E.L.; Cox, M.B., eds.

Torrance, CA: The American Lupus Society. 1993. 18 p.

Available from The American Lupus Society, 3914 Del Amo Boulevard, Suite 922, Torrance, CA 90503. (310) 542-8891 or (800) 331-1802. PRICE: $2.00.

This booklet was written for lupus patients. It provides a brief history of lupus, as well as the causes, diagnosis, symptoms, and treatment of the disease. A glossary is included. A Spanish version is also available.

Lupus Erythematosus in Braille.

Torrance, CA: The American Lupus Society. 1990. 53 p.

Available from The American Lupus Society, 3914 Del Amo Boulevard, Suite 922, Torrance, CA 90503. (310) 542-8891 or (800) 331-1802. PRICE: $10.00.

This publication is a Braille version of the American Lupus Society booklet, 'Lupus Erythematosus.' The publication was translated into braille by the Kentucky Department for the Blind. It discusses lupus erythematosus, its diagnosis, symptoms, and complications.

Lupus Erythematosus: What is L.E.?

Torrance, CA: American Lupus Society. April 1990. [2 p.].

Available from The American Lupus Society, 3914 Del Amo Boulevard, Suite 922, Torrance, CA 90503. (310) 542-8891 or (800) 331-1802. PRICE: Single copy free.

This foldout fact sheet discusses systemic lupus erythematosus (SLE), a chronic, inflammatory, autoimmune disease. The disease process of lupus is explained, and the criteria for classification of SLE are listed. Involved areas include the skin, joints, blood, heart, lungs and kidneys. Treatment consists of controlling symptoms and attempting to put the disease into remission through medication and lifestyle changes. The fact sheet also describes the American Lupus Society, its purposes and practices, and how it obtains funds.

Lupus News.

Rockville, MD: Lupus Foundation of America, Inc.

Available from the Lupus Foundation of America, Inc. 4 Research Place, Suite 180, Rockville, MD 20850-3226. (301) 670-9292 or (800) 558-0121. PRICE: $15.00 per year.

This is the official newsletter of the Lupus Foundation of America and is published three times a year. Issues typically include articles written by physicians on a variety of topics related to lupus. In addition, the newsletter provides updates on research and legislative issues. Book reviews and letters provide subscribers with additional and alternative sources of information.

Lupus Today.

Torrance, CA: The American Lupus Society. [8 p. average].

Available from The American Lupus Society, 3914 Del Amo Boulevard, Suite 922, Torrance, CA 90503. (310) 542-8891 or (800) 331-1802. PRICE: Call for subscription information.

This newsletter is published by The American Lupus Society. An average newsletter contains information about the symptoms of lupus, as well as about updates in lupus diagnosis, treatment and research. Other articles in the newsletter describe meetings and conferences of The American Lupus Society, and accomplishments and future goals of The American Lupus Society. Ordering information for books about lupus also is provided.

Lupus Words & Terms.

St. Clair Shores, MI: Michigan Lupus Foundation. 1983. 6 p.

Available from the Michigan Lupus Foundation. 26202 Harper Avenue, St. Clair Shores, MI 48081. (313) 775-8310. PRICE: Single copies free.

This pamphlet provides 114 definitions of medical words and terms that patients may encounter while reading about lupus erythematosus.

A Patient's Story.

Aladjem, H.

Rockville, MD: Lupus Foundation of America, Inc. 1986. 15 p.

Available from the Lupus Foundation of America, Inc. 4 Research Place, Suite 180, Rockville, MD 20850-3226. (301) 670-9292 or (800) 558-0121. PRICE: $1.75.

A story based on life, representing fears, frustrations, and experiences of people with lupus.

So Now You Have Lupus: An Aid to Understanding the Psychological Aspects of Lupus.
Epstein, L.; Romoff, B.
Torrance, CA: American Lupus Society. 1988. 20 p.
Available from The American Lupus Society. 3914 Del Amo Boulevard, Suite 922, Torrance, CA 90503. (310) 542-8891 or (800) 331-1802. PRICE: $2.00.

This booklet was written by two therapists who also have lupus. The authors describe systemic lupus erythematosus and discuss in detail the associated psychological aspects of the disease. These include stress, depression, body and self-image, effects of corticosteroids, and sexuality.

Tell Me About Lupus.
Hindman, A.
Torrance, CA: American Lupus Society. 1992. 8 p.
Available from The American Lupus Society. 3914 Del Amo Boulevard, Suite 922, Torrance, CA 90503. (310) 542-8891 or (800) 331-1802. PRICE: $2.00.

This booklet, written for young people, provides an introduction to lupus and explains how the illness is treated and managed.

Understanding Lupus.
Aladjem, H.
New York, NY: Macmillan. 1985. 247 p.
Available from the Lupus Foundation of America, Inc. 4 Research Place, Suite 180, Rockville, MD 20850-3226. (301) 670-9292 or (800) 558-0121. PRICE: $10.00.

This book is for patients, their families, physicians and other health care professionals and general readers who would like to know more about lupus and gain a better understanding of the person with lupus.

What is Lupus.
Akron, OH: Lupus Foundation of America, Akron Area Chapter.
Available from the Lupus Foundation of America, Akron Area Chapter. 942 N. Main Street, #23, Akron, OH 44310. (216) 253-1717. PRICE: Free.

This six panel brochure, written at a low reading level, describes the types of lupus, cause, signs and symptoms, who gets lupus, how it is discovered, and treatment.

Audiovisuals and Posters

Lupus: An Issue for the African American Community.

Columbus, OH: Columbus Chapter of the Lupus Foundation of America, Inc. 1993. 1/2-inch VHS videocassette (28 min.)

Available from Columbus Chapter of the Lupus Foundation of America, Inc. Attn: Steve Smith, 1203 Westwood Avenue, Columbus, OH 43212. (614) 221-0811. PRICE: $10.00 plus $3.00 handling fee.

This program is targeted to any person with lupus, but especially those from the African American community.

Lupus Disease: Its Effect on Women.

Washington, DC: National Public Radio, Horizons Series. 1988. Audiocassette.

Available from National Public Radio Tapes. 2025 M Street, NW, Washington, DC 20036. (202) 822-2323. PRICE: $12.50.

In this audiocassette, lupus patients discuss the symptoms and complications of their disease, and the daily struggles they must meet to live with lupus.

Lupus: Insights, Emotions, Encouragement.

Gill, W.; Gill, E. (Producers/Writers)

Columbus, OH: Columbus Chapter of the Lupus Foundation of America, Inc. 1987.

1/2-inch VHS (54 min.); 3/4-inch broadcast-quality copy; 1/2-inch VHS PAL mode copy; 1/2-inch edited copy (14 min.)

Available from the Columbus Chapter of the Lupus Foundation of America, Inc. Attn: Steve Smith, 1203 Westwood Avenue, Columbus, OH 43212. (614) 221-0811. PRICE: $28.25 (1/2-inch VHS); $43.25 (3/4-inch); $56.00 (1/2-inch VHS PAL); $11.25 (edited copy).

This video, featuring discussions with doctors, nurses, patients, and families and friends of patients, focuses on strategies for living and building constructive relationships. Also discussed are signs and symptoms of lupus, how the disease changes the patient's life, coping with those changes, medication, reactions of families and friends, and the role of support groups. An edited 14 minute version is also available, suitable for viewing by general audiences at health fairs or clinics.

Lupus: The Great Imposter.

Alexandria, VA: Lupus Foundation of Greater Washington, Inc.
1/2-inch VHS and 3/4-inch U-Matic. 14 minutes.

Available from the Lupus Foundation of Greater Washington. 515 A Braddock Road, 2C, Alexandria, VA 22314. (703) 684-2925. PRICE: $30.00 for VHS format, $45.00 for U-Matic format.

In this video, several individuals who suffer from lupus are introduced along with their friends and families. Viewers are informed about the basic nature of the disease and its effect upon the lives of those who suffer from it. The video also features physicians who discuss the disease, the state of research into finding a cure, and the kind of support the ongoing research effort requires. This film was awarded a certificate of merit from the American Medical Writers Association and a Golden Eagle Award from The Council on International Nontheatrical Events, both in 1987.

SLE: The Great Deceiver.

San Jose, CA: Lupus Foundation of America, Bay Area Chapter. 1986.
3/4-inch U-Matic, 1/2-inch VHS or Beta-Max II videocassette, or
110 35mm. slides with audiocassette (30 min.), color.

Available from Lupus Foundation of America, Bay Area Chapter. 2635 North First Street, Suite 206, San Jose, CA 95134. (408) 954-8600. PRICE: $50 (videocassette, purchase), $125 (slide/tape, purchase), $25 rental fee, applicable to purchase. Postage: $6 for slide/tape, $4 for 3/4-inch video, 3 for 1/2-inch video.

This two-part program was produced primarily for newly diagnosed lupus patients and their families. Patients need to be informed about the medical facts, methods of treatment, potential problems, how they can better manage their disease, and how to build better communication within their family and with others who play an important role in their lives.

Someone You Know Has Lupus.

Baltimore, MD: Maryland Lupus Foundation. 1988.
1/2-inch VHS videocassette (10 min.).

Available from Maryland Lupus Foundation. 7400 York Road, Third Floor, Baltimore, MD 21204. (410) 337-9000. (800) 777-0934 (MD only). PRICE: $25.00.

This ten minute video filmed at Good Samaritan Hospital in Baltimore, MD details what lupus is and isn't, diagnosis, symptoms, prevalence, occurrence and treatment. In interviews with Dr. Thomas M. Zizic, Associate Professor of Medicine at the Johns Hopkins University School of Medicine, and several lupus patients, perspectives of doctors and patients are presented. Suitable for patients and family members as well as the lay community.

Voices of Lupus.

New York: Wolf Pack and the Hospital for Special Surgery. 1992.

1/2-inch VHS videocassette (28 min.).

Available from Films for the Humanities and Sciences. P.O. Box 2053, Princeton, NJ 08543-2053. (800) 257-5126. PRICE: $149.00 purchase; $75.00 rental.

This program uses stong, positive role models to show how women afflicted with lupus can help themselves through peer group support and better communication with their physicians and families. This autoimmune disease affects more than a half-million women from diverse social, cultural and economic backgrounds. Interviews with patients and physicians demonstrate positive strategies which can help people with lupus, their families and their physicians cope better with this painful, unpredictable illness.

APPENDIX

MEMBERS OF THE TASK FORCE ON LUPUS IN HIGH RISK POPULATIONS

Sponsored by the National Institute of
Arthritis and Musculoskeletal and Skin Diseases

Chairpersons:

Lawrence E. Shulman, M.D., Ph.D.
Director
National Institute of Arthritis and
Musculoskeletal and Skin Diseases
National Institutes of Health
Bethesda, Maryland

Evie G. Dennis, Ed.D.
Superintendent
Denver Public Schools
Denver, Colorado

Matthew H. Liang, M.D., M.P.H.
Associate Professor of Medicine
Harvard Medical School
Robert B. Brigham Multipurpose Arthritis Center
Boston, Massachusetts

Members:

Milton H. Abram II, D.T.M.
President
Vice-Chairman of the Board for
Government Affairs
The American Lupus Society
Milwaukee, Wisconsin

Elaine Bratic Arkin
Consultant
Arlington, Virginia

Barbara D. Butler
Chairman
Government Relations Committee
Lupus Foundation of America
St. Louis, Missouri

Larry R. Crockett, M.B.A.
Director
Business and Industrial Assistance Division
School of Business Administration
University of Michigan
Ann Arbor, Michigan

Agnes H. Donahue, D.D.S., M.Sc.D., M.P.H.
Executive Director on Women's Health
Office of the Assistant Secretary for Health
DHHS
Washington, D.C.

Sandra Ferguson
Associate Council Director
United Methodist Church
Baltimore-Washington Conference Center
Baltimore, Maryland

Jacqueline Gibson, B.S.N.
National Black Nurses Association, Inc.
Little Rock, Arkansas

Marc C. Hochberg, M.D., M.P.H.
University of Maryland
Baltimore, Maryland

Sadako S. Holmes, R.N., M.P.H.
Executive Director
National Black Nurses Association, Inc.
Washington, D.C.

John M. Huber, M.S.
Executive Director
Lupus Foundation of America
Rockville, Maryland

Elizabeth Jameson
Attorney-at-Law
San Francisco, California

Purnell Kirkland, M.D.
National Medical Association
Inglewood, CA

James E. Lewis, Ph.D.
Professor of Medicine and
Senior Executive Officer
Department of Medicine
University of Alabama at Birmingham
Birmingham, Alabama

Hazel Farrar
Program Analyst
Office of Minority Health
Rockville, Maryland

Nancy McCormick-Pickett
Vice President
Prospect Associates
Rockville, Maryland

Vivian W. Pinn, M.D.
Director
Office of Research on Women's Health
National Institutes of Health
Bethesda, Maryland

Avis Pointer, Ph.D.
Vice President for Research and Development
National Medical Association
Washington, D.C.

Clarice D. Reid, M.D.
Chief
Sickle Cell Disease Branch
National Heart, Lung, and Blood Institute
National Institutes of Health
Bethesda, Maryland

Edward J. Roccella, Ph.D., M.P.H.
Coordinator
National High Blood Pressure Education Program
National Heart, Lung, and Blood Institute
National Institutes of Health
Bethesda, Maryland

Naomi F. Rothfield, M.D.
Professor of Medicine
Chief
Division of Rheumatic Diseases
School of Medicine and Health Center
University of Connecticut
Farmington, Connecticut

John Ruffin, Ph.D.
Associate Director for Research on
Minority Health
National Institutes of Health
Bethesda, Maryland

Peter T. Singleton, Jr., M.D., D.S.C., C.M.E.
Professor
Department of Medicine
Division of Immunology and Rheumatology
Moorehouse School of Medicine
Atlanta, Georgia

Karen V. Straaton, M.D.
Assistant Professor
Division of Clinical Immunology
and Rheumatology
Department of Medicine
University of Alabama at Birmingham
Birmingham, Alabama

NIAMS Staff Participants:

Julia B. Freeman, Ph.D.
Centers Program Director and Director
of Research on Women's and Minorities' Health
Extramural Program
NIAMS/NIH
Bethesda, Maryland

Steven J. Hausman, Ph.D.
Deputy Director
NIAMS/NIH
Bethesda, Maryland

John H. Klippel, M.D.
Clinical Director
Intramural Research Program
NIAMS/NIH
Bethesda, Maryland

Reva C. Lawrence, M.P.H.
Epidemiology/Data Systems Program Officer
NIAMS/NIH
Bethesda, Maryland

Michael D. Lockshin, M.D., F.A.C.P.
Director
Extramural Program
NIAMS/NIH
Bethesda, Maryland

Constance Raab
Director
Office of Scientific and Health Communications
NIAMS/NIH
Bethesda, Maryland

Barbara A. Weldon
Writer/Editor
Office of Scientific and Health Communications
NIAMS/NIH
Bethesda, Maryland

Contractor Participants:

Evelyn Brewster, M.A.
Senior Communications Associate
Prospect Associates
Rockville, Maryland

Catherine Burroughs, M.L.S.
Subcontract Manager
Prospect Associates
Rockville, Maryland

Barbara Bayer Kaplan, Ph.D.
Project Manager
Johnson, Bassin & Shaw, Inc.
Silver Spring, Maryland

Phyllis Payne, M.P.H.
Senior Associate
Johnson, Bassin & Shaw, Inc.
Silver Spring, Maryland

Under contract NO1-AR-0-2201 with the National Institute of Arthritis and Musculoskeletal and Skin Diseases, this kit was written by Phyllis Payne, Johnson, Bassin and Shaw, Inc.; graphic design and production by Crystal Hagan and Cathy Burroughs, Prospect Associates.

THE TASK FORCE ON LUPUS IN HIGH RISK POPULATIONS

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), a part of the National Institutes of Health, leads and coordinates the federal biomedical research efforts in lupus. The NIAMS conducts and supports considerable research on the causes, diagnosis, treatment, and prevention of lupus. The Institute also disseminates information and carries out special educational efforts.

In response to findings that certain populations have a higher incidence, prevalence, and mortality rate of systemic lupus, NIAMS initiated a Task Force on Lupus in High Risk Populations. The purpose of the Task Force is to develop educational strategies directed to patients, the public, and health professionals that may help improve the outcome of lupus in populations at high risk of developing the disease.

Task Force members include representatives from:

- Department of Health and Human Services' Office of Minority Health
- Public Health Service Coordinating Committee on Women's Health Issues
- Office of Research on Women's Health, National Institutes of Health
- Office of Research on Minority Health, National Institutes of Health
- Lupus Foundation of America
- The American Lupus Society
- National Medical Association
- National Black Nurses' Association
- Health professional and communications experts
- NIAMS program and public information staff

BEST COPY AVAILABLE

What Black Women Should Know About Lupus

NATIONAL INSTITUTES OF HEALTH
National Institute of Arthritis and Musculoskeletal and Skin Diseases

BEST COPY AVAILABLE

Prepared by the
NIAMS Task Force on Lupus in High Risk Populations
National Institute of Arthritis and Musculoskeletal and Skin Diseases
Box AMS
9000 Rockville Pike
Bethesda, Maryland 20892

The NIAMS, a part of the National Institutes of Health,
leads and coordinates the Federal biomedical research effort in lupus.

Do You or Someone You Know Have Signs of Lupus?

Lupus is a serious health problem that affects mainly young women. The disease often starts between the ages of 15 and 44.

People of all races may get lupus. However, lupus is three times more common in black women than in white women.

As many as one in 250 black women will get the disease.

What is Lupus?

Lupus is a disease that can affect many parts of the body. It can affect the joints, the skin, the kidneys, the lungs, the heart, or the brain. Only a few of these parts of the body are affected in most people.

Something goes wrong with the body's immune system in lupus. We can think of the immune system as an army within the body with hundreds of defenders (known as antibodies).

They defend the body from attack by germs and viruses. In lupus, however, the immune system becomes overactive and goes out of control. The antibodies attack healthy tissues in the body. This attack induces inflammation, causing redness, pain, and swelling in the affected parts of the body. This tendency for the immune system to become overactive may run in families.

What Does a Person with Lupus Look Like?

Many people with lupus look healthy.

What Are the Signs of Lupus?

The signs of lupus differ from one person to another. Some people have just a few signs of the disease; others have more. Lupus may be hard to diagnose. It is often mistaken for other diseases. For this reason, lupus has often been called the "great imitator."

Common signs of lupus are:

- Red rash or color change on the face, often in the shape of a butterfly across the bridge of the nose and the cheeks
- Painful or swollen joints
- Unexplained fever
- Chest pain with breathing
- Unusual loss of hair
- Pale or purple fingers or toes from cold or stress
- Sensitivity to the sun
- Low blood count

These signs are more important when they occur together.

Other signs of lupus can include mouth sores, unexplained "fits" or convulsions, hallucinations or depression, repeated miscarriages, and unexplained kidney problems.

What Causes Lupus?

We don't know what causes the immune system to become overactive. In some people, lupus becomes active after exposure to sunlight, infections, or certain medications.

Can You Catch Lupus From Someone Else?

No, lupus is not catching. You can't give it to someone else. Also, it is not a form of cancer. It is not AIDS.

Does Lupus Run in Families?

Most relatives of lupus patients do not develop the disease, but in some families more than one member gets lupus. If a relative of a lupus patient develops signs of lupus, she or he should see a doctor.

How Serious is Lupus?

Signs of lupus tend to come and go. There are times when the disease quiets down, or goes into remission. At other times, lupus flares up, or becomes active. Years ago, many people with lupus died. Now, with good medical care, most people with the disease can lead active, productive, and fulfilling lives.

Are There Different Kinds of Lupus?

There are three major types of lupus: (1) lupus that affects certain parts of the body (systemic lupus erythematosus), (2) lupus mainly of the skin (discoid or cutaneous lupus), and (3) lupus caused by medicine (drug-induced lupus).

Systemic lupus erythematosus, sometimes called SLE, is the most serious form of the disease. This type of lupus is the focus of this booklet. Systemic means that it may affect many parts of the body, such as the joints, skin, kidneys, lungs, heart, or the brain. This type of lupus can be mild or serious. If it is not treated, systemic lupus can cause damage to the organs inside your body.

Discoid and cutaneous lupus mainly affect the skin. The person may have a red rash or a color change of the skin on the face, scalp, or other parts of the body.

Drug-induced lupus is caused by a small number of prescription medications. The person with drug-induced lupus may have the same symptoms as the person with systemic lupus, but it is usually less serious. Usually when the medicine is stopped, the disease goes away. The most common drugs that can cause lupus are (1) procainamide used for heart problems, (2) hydralazine used for high blood pressure, and (3) dilantin used for seizures. Drug-induced lupus is usually found in older men and women of all races.

Does Sunlight Cause Lupus?

In some people, no matter what shade of skin, an attack of lupus may be brought on by being in the sun, even for a short period of time.

Do Men Get Lupus?

Yes, men get all forms of lupus. However, 9 out of 10 people who have lupus are women.

Why is Lupus More Common in Black Women Than White Women?

We do not know why the disease is more common in black women. However, research doctors supported by the National Institutes of Health are studying this problem. Researchers are studying why minorities are more inclined to get lupus, what causes it to start, and why is it mild in some and severe in others. Other researchers are studying why the signs of lupus differ between black women and white women.

What Should You Do if You Think You Have Lupus?

You should see a doctor or a nurse and be examined and tested for lupus. They will talk to you and take a history of your health problems. Many people have lupus for a long time before it is detected. It is important that you tell the doctor or nurse about your symptoms. (The checklist in the back of the booklet may be helpful.)

How is Lupus Treated?

The doctor may treat each lupus patient in a different way because the signs of lupus often differ from one person to another. The doctor may give aspirin or similar medicine to treat the painful, swollen joints and the fever. Creams may be prescribed for the rash, and stronger medicines prescribed for more serious problems.

Is There a Cure for Lupus?

At this point, lupus cannot be cured. However, in many cases, signs of the disease can be relieved. The good news is that with the correct medicine and by taking care of themselves, most lupus patients can hold a job, have children, and lead a full life.

Outlook

The outlook for lupus patients has greatly improved. Research doctors supported by the National Institutes of Health are studying many aspects of lupus, such as what goes wrong with the immune system, why the disease runs in families, how lupus causes damage in the body, and why it can lead to repeated miscarriages. Others are researching why lupus is so much more common in women, especially black women. Researchers

have learned a great deal about lupus and are studying new ways to treat and, hopefully, prevent the disease. The future holds great promise for improving the health of all Americans who have lupus.

Awareness

Please share this booklet with your family and friends. Someone you know or care about may have lupus.

For further information on lupus, see your doctor or health clinic and contact your local chapter of the following organizations:

Lupus Foundation of America, Inc.
4 Research Place
Suite 800
Rockville, Maryland 20850-3226
(301) 670-9292
(800) 558-0121

The American Lupus Society
3914 Del Amo Blvd.
Suite 922
Torrance, California 90503
(310) 542-8891
(800) 331-1802

Both of these groups can provide more detailed information on lupus through free pamphlets and newsletters. They also have pamphlets in Spanish. The two groups also can refer people to doctors and clinics who see a lot of lupus patients.

Checklist on Signs of Lupus

Use this page to make notes to take to your doctor

_____ Red rash or color change on face, often in the shape of a butterfly across the bridge of the nose and the cheeks

_____ Painful or swollen joints

_____ Unexplained fever

_____ Chest pain with breathing

_____ Unusual loss of hair

_____ Pale or purple fingers or toes from cold or stress

_____ Sensitivity to sun

_____ Low blood count

These signs are more important if they occur together.

This booklet is not copyrighted. Readers are encouraged to duplicate and distribute as many copies as needed. Additional copies are available from the NIAMS Task Force on Lupus in High Risk Populations, National Institute of Arthritis and Musculoskeletal and Skin Diseases, Box AMS, 9000 Rockville Pike, Bethesda, Maryland 20892. Comments and suggestions about this booklet or other possible booklets are welcome.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
National Institutes of Health
National Institute of Arthritis and Musculoskeletal and Skin Diseases

NIH Publication No. 93-3219
September 1993

BEST COPY AVAILABLE

PLEASE LET US KNOW

Your comments help us evaluate and improve our public information campaign! Please take a moment to complete and mail this response form.

1. Have you used or do you plan to use the following materials?

   - ❒ How To Develop a Lupus Awareness Program
   - ❒ How To Work With the Media
     - ❒ 20-, 30-, or 60-second live announcer scripts
     - ❒ Sample cover letter to public service directors to accompany PSA's
     - ❒ Fill-in-the-blanks press release
     - ❒ Sample letter to the editor
     - ❒ Sample feature story pitch letter
     - ❒ Sample newsletter article--"Health Watch: Black Women and Lupus"

2. Have you used or do you plan to use the following camera-ready materials?

   - ❒ *What Black Women Should Know About Lupus*
   - ❒ Poster
   - ❒ Facts About Lupus and Black Women
   - ❒ Checklist of Symptoms
   - ❒ Test of Lupus Knowledge
   - ❒ Bill stuffers/bookmark
   - ❒ Stationery
   - ❒ Logos

3. Did you contact or refer to any of the following resources?

   - ❒ The Lupus Foundation of America
   - ❒ The American Lupus Society
   - ❒ The National Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse
   - ❒ Resources for Community Program Planning
   - ❒ Educational Materials About Lupus

4. Comments:

Name: _____
Title: _____
Organization: _____
Address: _____
City: _____ State: _____ Zip: _____
Telephone: _____

9/93

NIAMS Task Force on Lupus in High Risk Populations
National Institute of Arthritis & Musculoskeletal & Skin Diseases (NIAMS)
Box AMS
9000 Rockville Pike
Bethesda, Maryland 20892

ORDER FORM

To order extra copies of the kit or the booklet entitled *What Black Women Should Know About Lupus*, please complete this order form. The kit is limited to one copy per order. The booklet is available in quantities from 1 to 50 copies per order.

❒ Please send us one copy of the kit.

❒ Please send us _____ copies of the booklet.
(1 to 50)

NAME:_____

TITLE:_____

ORGANIZATION:_____

ADDRESS:_____

CITY:_____STATE:_____ZIP:_____

TELEPHONE:(____)_____FAX:(____)_____

Mail Order Form To:

NIAMS
Task Force on Lupus in High Risk Populations
Box AMS
9000 Rockville Pike
Bethesda, MD 20892
(301) 496-8188

or

FAX Your Order To: NAMSIC at (301) 480-6069

9/93

NIAMS Task Force on Lupus in High Risk Populations
National Institute of Arthritis & Musculoskeletal & Skin Diseases (NIAMS)
Box AMS
9000 Rockville Pike
Bethesda, Maryland 20892

What Black Women Should Know About Lupus

Common Signs of Systemic Lupus

- Red rash or color change on the face, often in the shape of a butterfly across the bridge of the nose and the cheeks
- Painful or swollen joints
- Unexplained fever
- Chest pain with breathing
- Unusual loss of hair
- Pale or purple fingers or toes from cold or stress
- Sensitivity to the sun
- Low blood count

These signs are more important when they occur together.

For further information on lupus, see your doctor or health clinic and contact your local chapter of the following organizations:

Lupus Foundation of America, Inc.
4 Research Place
Suite 800
Rockville, Maryland 20850-3226
(310) 670-9292
(800) 558-0121

The American Lupus Society
3914 Del Amo Blvd.
Suite 922
Torrance, California 90503
(310) 542-8891
(800) 331-1802

BEST COPY AVAILABLE

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service National Institutes of Health
Task Force on Lupus in High Risk Populations

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service, National Institutes of Health
National Institute of Arthritis and Musculoskeletal and Skin Diseases
NIH Publication No. 93-3445
September 1993

BEST COPY AVAILABLE